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The proceedings, as reported by a science writer, consider family components of retardation. Stephen Richardson presents some study findings on family components in mental retardation; Bernard Farber surveys the family relationships of institutionalized and non-institutionalized retarded children; and Irving Tallman discusses family theory as it relates to retardation. General discussion is summarized as are the participants' remarks on sociological aspects of retardation research and specific research potential. Also listed are 56 questions for possible research, suggestions for future action, 31 references, and the conference participants' names, titles, and addresses. (LE)

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THE SOCIAL SCIENCES AND MENTAL RETARDATION: FAMILY COMPONENTS

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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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THE SOCIAL SCIENCES AND MENTAL RETARDATION: FAMILY COMPONENTS

Report of a Conference

January 8-9, 1968

Conference Room 2, Building 31

Bethesda, Maryland

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
OFFICE OF EDUCATION

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National Institute of Child Health and Human Development
Bethesda, Maryland

FOREWORD

The National Institute of Child Health and Human Development is particularly grateful to the participants who contributed so much valuable thinking during the conference reported in this document. We feel strongly about the importance of a greater emphasis on the social sciences in mental retardation research, and this conference group has helped us to take an important initial step in stimulating interest and action. Free-lance science writer Leora Wood Wells has woven the discussion of the participants into this summary report so that others may share in further thought and action in the field of social studies of mental retardation.

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and Human Development

Conference on Social Sciences and Mental Retardation: Family Components

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CONTENTS

FOREWORD.....i

LIST OF PARTICIPANTS.....iii

CONFERENCE BACKGROUND AND PURPOSES.....1

FAMILY RESEARCH IN MENTAL RETARDATION.....4

Family Components in Mental Retardation--Some Study Findings: Dr. Richardson.....4

Family Relationships of Institutionalized and Non-Institutionalized Retarded Children: Dr. Farber.....13

Family Theory as it Relates to Mental Retardation: Dr. Tallman.....15

General Discussion.....21

MENTAL RETARDATION RESEARCH.....26

Sociological Aspects of Mental Retardation Research.....26

The Specific Research Potential.....30

SOME POSSIBLE RESEARCH QUESTIONS.....32

FUTURE ACTION.....37

REFERENCES.....39

CONFERENCE BACKGROUND AND PURPOSES

Mental retardation is a multifaceted problem with medical, psychological, educational and social components. The National Institute of Child Health and Human Development has responsibilities for research and research training in the biomedical, behavioral, and social aspects of mental retardation and related aspects of human development. Some of these areas have received a great deal of attention in recent years from the scientific community. The sociological dimensions, however--which are crucial to an understanding of the etiology of mental retardation and the development of preventive and ameliorative measures--have received relatively little attention.

To examine the reasons for this gap and to find ways to overcome it, the NICHD asked a small group of sociologists to meet at NIH on January 8-9, 1968, to discuss the role of the social sciences in mental retardation research. The emphasis in this first of a planned series of conferences, was on the family components of retardation--the effects of the child and family as viewed from the perspective of social research, clinical practice and family theory. How can the social sciences contribute to an understanding of the problem and ways of coping with it, where do significant research gaps lie, and what can be done to stimulate social science research to fill these knowledge gaps?

On opening the conference, Chairman Michael Begab pointed out that the complexity of the mental retardation problem requires that theory and research from a broad range of sciences be brought into play if the interacting forces which cause or contribute to mental retardation are to be understood. Without such understanding, programs of prevention and treatment are not likely to succeed.

Psychiatry, psychology, psychoanalysis and other helping professions have in years past, traditionally concerned themselves with the problems of the individual <u>in</u> society and his adaptive relationships to his environment. Socialization and personality development have been seen primarily as the products of an incessant struggle between innate biological drives and cultural restraints. More recently, these concepts have assumed a broader perspective. The complexities of the human organism are now being interpreted in the light of social conditions which men create and to which they are, in turn, subject. The economic forces which shape social organization, the norms, values, and mores which regulate conduct, the social classes to which people belong and the opportunities available to achieve their goals are all seen as

determinants of development and behavior. Thus, the individual and society are seen as inseparably linked and mutually interacting forces.

Mental retardation is well adapted to this frame of reference. Its causes are many, and its consequences for the individual range from nearly normal functioning to total dependency. Its effects on the family and the community are at the very least disruptive and at the worst acutely destructive. Effective programs of prevention and treatment depend not only on helping the individual but on building constructive family and public attitudes and manipulating and improving social conditions.

Mental retardation is by definition bidimensional, involving both low intelligence and impaired behavior. Both of these dimensions are relative qualities, subject to change through a variety of therapeutic procedures. Who is defined as retarded depends to a considerable extent on prevailing educational and cultural standards and the social expectations of the community.

In our society--with its stress on the American Dream of success for all--the retardate is a symbol of failure. In the economy, he may be an underproducer of goods and an overconsumer of the tax health-and-welfare dollar. In the neighborhood, he may be an object of suspicion and distrust. In the family, he is almost inevitably a burden, even when he is regarded as a valued and beloved member. In brief, retardation may be the core, the cause, or the consequence of social dysfunction.

The family components of mental retardation are, perhaps, the most critical aspects of social dysfunction, and are as diverse as the phenomenon itself. Two principal types of families can be identified in which mental retardation is a key factor:

- families in which the parents are "normal" and there is a marked disparity between their intellectual level and that of their organically damaged child

- families in which the parents are socially disadvantaged, undereducated, and often intellectually limited. The child is thought to be neurologically intact, but functions at a borderline or mild level of retardation.

Neither of these family types is a discrete entity. Being of "normal" or "average" intelligence does not preclude having a neurologically intact but intellectually subnormal child. Conversely, being disadvantaged is not a barrier to producing a neurologically damaged child; indeed, the incidence of handicapping conditions including mental retardation is greater among high-risk socially and

economically deprived families. Nevertheless, these two basic family types are so different in so many significant ways that failure to distinguish between them can seriously distort understanding of the problems of mental retardation.

Much of the retardation research has focused on the impact of the problem on family life--the intrafamily dynamics it brings into play and the changing role patterns and adaptive strategies that develop. The converse proposition, the impact of the family on the retarded child's development, personality, and emotional status has received less attention. The impact of the child's constitutional endowment on parent-child interactions, the role of the family in the socialization of the child, and the affects of parental attitudes and child management techniques are all critical in this context. And, of course, families are not islands unto themselves. Each is subject to a host of ethnic, religious, socioeconomic and cultural values which affect how they perceive and cope with the problem.

Full consideration of these elements Dr. Begab concluded, was admittedly an ambitious goal for a two-day conference. But at least, he said, a beginning will have been made in defining areas of potential research whose significance is incompatible with the history of their prolonged neglect.

FAMILY RESEARCH IN MENTAL RETARDATION

As a basis for discussion of the role of sociology in relation to mental retardation research, several participants were asked to report on specific aspects of the interrelationship between families and mental retardation problems. These presentations stimulated both general discussion and specific examination of questions relating to research.

Family Components in Mental Retardation--Some Study Findings: Dr. Richardson

Dr. Stephen A. Richardson, Research Director for the Association for Aid to Crippled Children, discussed some of the problems of mental retardation research and the findings of recent sociological studies which have contributed to an understanding of the family components in mental retardation. For twelve years, Dr. Richardson said, he has been interested in the relative contribution of social/environmental factors and physiological insult to the causes of handicapping.

It is important, he said, to define what we mean by mental retardation. The distinction between mental subnormality and mental illness often becomes blurred, in part, perhaps, because behavioral disturbances are frequently associated with mental retardation. The President's Panel on Mental Retardation estimated the incidence of mental retardation as being approximately 3% of the population, but this figure is not very meaningful because so many different criteria are used to define the term.

The criteria most often used to define mental retardation are social competence and the ability to assume certain personal and social responsibilities; school performance; and performance on intelligence tests. Each of these has major drawbacks.

Social competence is a function of environment. The same individual may be perfectly competent to function in a milieu which has relatively undemanding standards of behavior yet incompetent in a more challenging environment. Different societies also have different expectations of behavior at each age level, so that a child of a sophisticated cultural group is expected to function at a more advanced level than a child of the same age from a different cultural group.

School performance may also reflect the particular environment. A slum child may function at average level among classmates of similar background but his school performance would be considered severely

retarded if he were suddenly placed in a school with classmates of higher socioeconomic level backgrounds.

The limitations of intelligence tests are widely recognized, as they are often based on concepts entirely outside the range of experience of some population groups. For example, the normative curves used for World War II inductees were derived from industrialized urban populations. When these norms were applied to people from remote rural areas, 50-60% were rejected.

Many other factors affect test performance. Some children are erroneously classified as mentally retarded because they have an unrecognized vision or hearing deficit. Some children have the capacity to translate auditory input (like the tapping of a pencil) into visual outputs (like pencilling a series of spaced dots) which match the pattern of the sounds. Other children cannot do this. This does not mean they are subnormal: it means they have a different range of functioning on this particular item.

Numerous attempts have been made to determine the true prevalence of mental retardation. Studies usually show a sharp increase around age 5 with a peak around age 15. This may give a deceptive suggestion of a very low incidence of mental subnormality during the early years of life. Actually, this curve represents, in part, the universal screening effect of the school experience. Mild subnormality which pre-existed is often first diagnosed at school age. There are at present no reliable instruments for precise measurement of intelligence during the early years of life, so it is often only the severe cases involving central nervous system damage that are identified prior to school entry.

The apparent drop in prevalence after the peak at age 15 shows less about actual intelligence levels than it does about social custom. Many people who have been considered retarded during their school years "disappear" back into the community as they reach adulthood. There they face an entirely different set of demands which stress practical, day-to-day adjustments rather than intellectual performance. If they are able to function reasonably well, they are no longer classified as mentally retarded even though their intellectual capacity is no greater than it was previously.

On the other hand, the individual of borderline intelligence who manages to pass through childhood and the school years without being identified as mentally retarded may also be classified as normal in adulthood, even if he functions at a decidedly retarded level compared with the rest of the adult population. These phenomena

raise questions about the way our school systems are organized. Teaching proceeds from the assumption that all children of the same chronological age have more or less the same ability, which is obviously not the case. Children who are sufficiently retarded that they cannot conform to the expectation for their age levels are faced with perpetual defeat and are stigmatized by the label of retardation as if it were a fixed rather than a relative condition. Such stigmatization has the additional hazard that teachers of children who are labelled as retarded are apt to treat them accordingly and may fail to stimulate them to their maximum level of performance.

On the other hand, both parents and teachers sometimes swing to the opposite extreme in their efforts to protect subnormal children from being stigmatized. When special education for mentally retarded children was begun in one school system, many of the teachers and parents reacted with a "fate-worse-than-death" attitude. They did everything they could to keep the children from being labelled as retarded and sent to the special school, thus depriving them of the beneficial effects of education tailored to their particular needs and capabilities.

Some of the prejudice surrounding education of the retarded is being overcome, but many stereotypes remain. Some other countries have advanced further in this than the United States; teachers of the retarded are required to have particularly high qualifications and they receive higher salaries than teachers of normal children.

The lasting effects of stigmatization as retarded have been pointed up in Robert Edgerton's recent book, The Cloak of Competence. This is a report of the coping mechanisms of people who have been institutionalized as mentally retarded and then released into the community as adults. Some are reabsorbed with relative ease. For example, the women who married after their release were often able to maintain marital stability and were considered "good wives" by their husbands even though their mental limitations were recognized. Others of the retardates, both men and women, had job and personal adjustment difficulties which were complicated by their sense of shame and their fear that their past identification as retardates would be discovered. We need to find ways to give the retarded the help they need without stigmatizing them for the rest of their lives.

Exact information on the prevalence of mental retardation among eight to ten year olds in a total community has been provided by a study done in Aberdeen, Scotland, under the joint sponsorship of the University of Aberdeen and the Association for Aid to Crippled Children. The study was under the direction

of Sir Dugald Baird, and Dr. Richardson was a member of the multi-disciplinary research team. The findings are being prepared for publication in book form.

Because the obstetrical and medical history of every child in the community is a matter of record under the British National Health System, Dr. Richardson said, it was possible to determine the incidence of mental retardation with considerable accuracy, especially since 1) Aberdeen has a very stable population, and 2) standards of obstetrical care are uniform among all social classes. About 9,000 children were included in the study sample.

Among children between the ages of 8 and 10 who have been defined as mentally subnormal by both health and education authorities and placed in special institutional or educational facilities, the overall incidence was found to be 12.6 per 1000. Of the 12.6, 3.7 per 1000 had IQs below 50 and 8.9 per 1000 had IQs of 50 or above. This 3.7 figure agrees closely with most other studies that have been done. These are severely retarded children who would be defined as mentally subnormal in almost every culture.

In order to identify, also, children who were subnormal but had not been assigned to special facilities, all children in the community were given a screening test at age 7. All children with test scores of less than 75 were retested individually to verify the accuracy of the initial findings. As a result of these tests, an "iceberg" group of an additional 15.6 per 1000 was shown to have some degree of mental subnormality, raising the estimated overall incidence to 28.2 per 1000. Among the non-institutionalized children whose test scores were below 75, prevalence was 10 times as great among children from the lowest social class as among those from the upper class.

Among the children in special facilities for the mentally subnormal, distribution followed the same pattern. The lowest prevalence (1.3 per 1000) was found in children of non-manual workers. The prevalence increased in reverse proportion to social class with the greatest prevalence (32.6 per 1000) in children whose parents were in unskilled manual occupations. In other words, there was almost a 10-fold difference in the overall prevalence between children of the upper and the lowest social class.

When these figures were broken down by the degree of mental subnormality, however, the relationship to social class level appeared in a somewhat different light. The incidence of severe mental subnormality was constant across all social classes. The incidence of mild retardation increased from zero per 1000 in the

upper social classes to 24.9 per 1000 in the lowest social class. In general, these findings are consistent with the findings of studies done elsewhere.

However, some investigators felt that the apparent high correlation between mild retardation and descending levels of social class might be somewhat misleading. Upper class parents tend to be more sensitive about stigmatization and are apt to conceal mild retardation by making special arrangements for their children which lower class parents cannot afford to do. The fact that the "iceberg" group of noninstitutionalized children showed the same 10-fold class difference in prevalence as the institutionalized children appears to rule out this bias, Dr. Richardson said.

The school performance of the "iceberg" group has not been examined. A followup study is planned to compare what becomes of children who have been educated in special facilities with the "iceberg" group of noninstitutionalized children in the years after they leave school.

It is well known that there is a higher proportion of central nervous system damage among the severely subnormal than among those with mild levels of subnormality. However, some cases of CNS damage do exist among children with IQs of 60 or better. The Aberdeen study showed some surprising social class distinctions among moderately retarded, organically impaired children in special facilities. As with severe retardation, distribution of these moderately retarded cases involving CNS damage was random across social classes I through IV. But in the lowest class, V, there was a seven-fold increase as compared with any other social grouping. The reasons are difficult to assess, but one possible interpretation is that a child with moderate CNS damage reared in circumstances which optimize his intellectual functioning might be able to remain in the normal school system, while a child with an identical level of biological handicap, reared in an environment where conditions for development of his intellectual capacities were poor would function at too limited a level to make this possible.

Neurological studies were done only on the children in special facilities for the retarded. Further studies are needed to determine how many of the "iceberg" group of children who are mildly retarded but are in the normal school system have CNS damage and how this correlates with social class in the total child population. It may be significant that the incidence of retardation is higher among siblings of the institutionalized children with the mild range of retardation (IQs above 60 but below 75) and no organic damage than among siblings of children with CNS damage. This

suggests the importance of many social factors. We need to know what specific experiences children of various social classes with or without CNS damage have which affect their level of intellectual functioning.

With children who have massive physiological damage, the extent to which development can be modified by different kinds of socio-environmental circumstances is very limited. There is much greater latitude when the child is physiologically intact, much greater hope of modification even when retardation is severe.

However, in many cases it is difficult to be sure whether or not a child has suffered CNS damage, and it is not always a point of major significance. The important point is the range of function an individual has. Two children may show the same IQ on tests. One may have achieved this through a set of optimal social conditions which enable him to function at the peak of his potential. The other may function poorly and below his true potential because he has come through a set of environmental experiences which have severely reduced his intellectual level.

We need to identify more clearly the many variables in each social class that are associated with mental subnormality. The Aberdeen study provided some evidence to suggest relationships to such factors as size of family, ordinal position of the child, level of family disorganization, area of residence, chronic unemployment, poverty, and overcrowded housing conditions. In families of this study group in which the three measures of membership in social class V coexisted--residence in a particular deprived area of town, ordinal position, and family size including more than 5 children were combined--the prevalence of mental retardation in the 8 to 10 year olds was 12 to 14 times greater than the overall prevalence.

Social mobility of the mother was an important variable. The incidence of retardation is significantly higher among children of mothers who have moved downward in terms of social class from where they were before marriage. Care must, however, be taken not to jump to cause-and-effect conclusions. For example, physiological as well as social influences must be considered. We know that the frequency of almost all forms of obstetrical risks is greatest in the lowest social classes.

The age of the mother did not appear to be a particularly important variable. However, ordinal position of the child was a significant variable. Prevalence of retardation was higher among fifth, sixth, seventh or eighth children than among earlier children.

Frequency of pregnancy and wearing out of the reproductive capacity may be factors. Whether prevalence of retardation would continue to rise with still larger families is not known, because of the high rate of voluntary sterilization in the lower social class families after the birth of the later children.

In upper class families in Aberdeen, this pattern is reversed. The incidence of mental subnormality is higher among first born children than among later children. The upper class families tend to have fewer children, both by social custom and because the upper class mothers are often professional women who start their child-bearing at a later age. They seldom have fifth, sixth or seventh children; hence retardation, if it appears, must obviously afflict the first child or two in the family.

What effect having a mentally subnormal child has on family planning depends on a variety of factors. One is the age at which the retardation is recognized. If it is not identified until the child is school age, several additional children may have been born during the interval. The type of retardation is influential. Parents are more apt to decide not to have additional children if the retardation is known to be due to a genetic defect. The ordinal position of the child again enters the picture; retardation is perceived as much less of a threat by parents who have several children already than by parents with a first born child in whom they have an enormous emotional investment. Economic and physical resources are other factors; parents of a retarded child may limit their families because they feel they cannot take care of additional children.

The adjustment of families to the presence of a retarded child is, of course, never easy. The parents of any handicapped child begin with no experience and a stock of over-simplified stereotypes. They observe the child in terms of his actual behavior and their expectations of him. How early, how rapidly and how far he falls below their expectations depends on the type and severity of retardation he has; and how far he falls affects the attitudes his parents show toward him. One yardstick parents use to measure the behavior of their child is the behavior of his peers, and this varies with social class. When a discrepancy exists, it will appear larger in the upper social classes where the expectation is for all children to function as if they had IQs of at least 115. It may be scarcely noticeable in social classes where the expectation is for children to function as if they had IQs of 85. Mental subnormality is perceived as a much more profound dislocation and a more extreme form of deviance by upper class parents (who are apt to think their child retarded if he doesn't get into an Ivy

League college). Thus mental subnormality is not a uniform or absolute entity but must be evaluated in relation to many factors.

The way families of retarded children interact with the many institutions of society is a critical issue. They may manage quite well on their own until some crisis arises. The onset of sexuality is often seen as such a crisis. There is, however, much less concern in cultures where premarital sexual relations and pregnancies are considered unexceptional.

Tizard and Grad have done a comparative study of characteristics of families retaining severely retarded children at home and those who place their children. Most who keep the children at home, they found, do so until an accumulation of illnesses, fatigue, and general breakdown of the family forces them to make the change. This suggests that some provision should be made for short term stays in institutions or foster care to give parents a respite from the constant strains of caring for the retarded child.

The effects of different types of care on the development of retarded children is an important issue which needs further study. Care of retarded children has been routinized in many institutions to such an extent that even bathing and dressing has been done on an assembly line basis, with one nurse undressing the child, the next bathing him, a third drying him and the fourth dressing him. This provides no satisfying continuity of relationships for either nurse or child.

In other ways, also, institutions have diminished the opportunities of the retarded to establish any sense of personal identity or any relationship with the community. Patients are often allowed few personal possessions. The institution itself is traditionally set in a remote rural area rather than near the active center of the community and the homes of the patients' relatives. Besides having a directly isolating effect on the patients, such locations make it difficult to recruit and hold qualified personnel.

Because the institutions are so large, they have had to establish their own medical, educational and recreational facilities, thus further segregating the inmates from contact with the normal world through the use of community facilities. In England there is now a trend toward decentralized facilities near the homes of those who need service and small enough to be able to utliize the regular medical, social and recreational facilities of the community.

Contact with the community benefits the retarded person in two ways. It gives him opportunity to test his capabilities in relation to normal people, and it helps to overcome some of the stereotypes about the retarded that have developed because so few people have actually had first hand contact with people who are mentally subnormal. The differential effects of care in large traditional institutions and small local facilities are now being studies.

The extreme differences in developmental potential in different types of institutions was pointed up almost accidentally, Dr. Richardson said, by studies of a group of orphaned children who had been placed in a State institution in Iowa. A high percentage were functioning at a mentally subnormal level, although they had been institutionalized not because of retardation but because they had no parents and no homes. Thirteen of these children, under 3 years of age, were transferred to the facility for mentally retarded women. When the children were retested two years later, those who had been transferred showed a marked increment while those who had remained in the orphanage setting showed a marked drop in intellectual ability.

A followup study 20 years later showed that all 11 survivors of the 13 who had been transferred were functioning as normal members of the population while many members of the group who had not been transferred had remained retarded and had spent a major portion of their lives in institutions. The reason seemed to be that the children who had been transferred became the pets and playthings of the mentally retarded women and the residential staff. They were showered with attention and affection. The orphanage children, on the other hand, lived in conditions of overcrowding and understaffing in which they received minimum attention. This has obvious implications for experimental manipulation of the environment to diminish the deficits of mental retardation and upgrade intellectual performance to the highest level of individual capacity.

A three year experimental program in London under the direction of Tizard has recently been completed. From 32 severely retarded Mongoloid children ages 6 and 7 in a large, hospital type institution, Tizard transferred 16 to a special facility in which the program was designed around the types of experiences children need to maximize social development. Staff members were oriented toward child development through the Montessori method rather than toward pathology. Cost and the ratios of staff to children were kept comparable in the two programs. There were striking developmental differences in the children raised in these two different settings.

All of these recent studies have tremendous implications for both research and services, Dr. Richardson concluded. It is evident that mild subnormality poses the greatest problem numerically, yet the thrust of most research and most services is toward severe retardation. In relation to mental retardation, there has been a tendency to swing from one extreme to another: from thinking if we just find the right therapy, we can make everybody function normally, to thinking there's really nothing we can do for retarded people. Either assumption is ridiculous. False optimism develops when a particular study shows fantastic upswings in IQ occurring in certain children. The fact that the true range of functioning of these children had not been determined and that children had been improperly classified to start with, is ignored. Questions often raised about background and family relationships may be much too narrow in scope and may lead to erroneous placement in institutions when other forms of care might be more effective in overcoming the handicaps. Development of guidelines for overall evaluation of children has been neglected as an area of research and would be an appropriate concern for sociologists.

Family Relationships of Institutionalized and Non-Institutionalized Retarded Children: Dr. Farber

Dr. Bernard Farber of the Institute for Research on Exceptional Children at the University of Illinois discussed briefly some of the studies that have been done on institutionalization versus home care of the retarded. As long ago as 1857, Dr. Farber said, Samuel Gridley Howe wrote that his choice, if he were to establish additional facilities for care of the retarded, would be to have the children live at home and attend day school or live in small groups in homes in the village. A whole series of studies done during the century since Howe expressed this viewpoint have pointed to the fact that retarded children do not develop as well in large institutions as they do in other settings. Yet we still have many large institutions which inflict still further deficits on children who are already among the more severely retarded. One study, however, indicates that the IQ of institutionalized children from comfortable homes tends to drop while that of children from severely disorganized homes tends to rise.

In the State institutions a high percentage of the retarded children are from highly disturbed families of poverty level. Because of the high costs, only the relatively wealthy can send their children to private institutions.

Several studies have been done to determine which families institutionalize their children and why. One of Dr. Farber's

studies surveyed about 230 families; another covered about 360 families who were questioned about various aspects of their attitudes toward their retarded children. The data have been analyzed for religious affiliation but not ethnicity, although the ethnic data are available.

The studies showed that Jewish families were least apt to institutionalize their children, Catholics were next, and Protestants were the most apt to do so. This was especially true when the level of marital integration was low. When Jewish families did institutionalize their children, it was usually because other severe problems in addition to the retardation existed in the home. The effect of the retarded child's presence on the other children was frequently cited as a principal factor, as was the influence of the extended family group including the grandparents.

A social class distinction was present, with working class families more apt to institutionalize their children than upper class families. However, such institutionalization often represented not a family decision but intervention of welfare agencies, the police, school, or other community agencies. In such cases, the family did not view the child as having been permanently ejected from the home but considered his institutionalization in much the same category as commitment to a training school or penal institution. They maintained visiting and other contacts during his absence, which they viewed as temporary, and functioned on expectation of his later return to the family group.

Families with a retarded child in the home were compared with families with an institutionalized child in relation to the personalities of the next oldest sibling. It appeared that girls whose retarded younger siblings lived at home had more personality problems than those whose siblings were in institutions. This difference did not seem to hold for boys. The sex of the retarded child did not seem to be a crucial factor. Since the data were obtained from the mothers, they cannot be considered entirely objective and reliable.

Interviews with the siblings indicated that those who had a high level of interaction with their retarded siblings were apt to give high rank to serious, altruistic life goals that had to do with devotion to a worthwhile cause. Those with a low level of interaction with their retarded siblings expressed more interest in social-emotional goals like having a lot of friends and getting along well with them. These data were not broken down by sex.

The impact of retardation, particularly of a son, appeared to be stronger and more lasting on fathers than on mothers. The reaction of the mothers varied with social class. Middle class mothers were more inclined to go to pieces over the information than lower class mothers. Reaction was particularly intense in the parents at the point where the physician or psychologist first labeled the child as severely retarded and with no hope of ever "growing up."

On the question of social mobility, the data showed that the earlier in the marriage the retarded child was born, the less chance there was of upward social mobility. Families of higher social class who placed their children in institutions were less affected in their social mobility aspirations than those whose children remained at home.

Some studies have indicated that the presence of special programs for the educable retarded in the community reduces the rate of admission to State institutions. One effect of this is that the proportion of severely retarded in the State institutions is increasing. One study suggested, however, that parents tend to become disillusioned with special education programs.

One study shows that the relationship between the mother and her own siblings is an important variable in how well a retarded child does in special education classes. Children whose mothers have close and frequent contact with their extended family groups progress better than those whose mothers have little contact with their siblings and know little about their lives or their work. This suggests that certain qualities in kinship relationships extending beyond the nuclear group relate in some way to the child's ability to respond and develop when given the opportunity.

Family Theory as it Relates to Mental Retardation: Dr. Tallman

Drawing from his own research and that of other social scientists, Dr. Irving Tallman of the Family Study Center, University of Minnesota, discussed two principal aspects of family theory as it relates to mental retardation. We need to ask two questions, he said:

- What is the impact of mental retardation on the family?
- How does the family cope with mental retardation?

To assess the impact of mental retardation, we have to examine what meanings mental retardation has for families; how these meanings

vary in different subcultures and with different types and degrees of severity of mental retardation; and to what extent the meanings are altered by social changes like urbanization and the decline in job opportunities for unskilled manual workers.

To evaluate the way families cope with mental retardation, we have to look at how the presence of a retarded child affects family organization or disorganization; how role allocations and division of labor are altered as a result of the presence of a retarded child; what roles are assigned to the retarded child; to what extent family goals are altered, reinforced or abandoned; and what internal and external resources a family has to help it cope with the situation.

We can look at the family, Dr. Tallman said, in three different ways:

- as an institution among other institutions in society
- as a social organization
- as a small group of interacting personalities.

Each of these aspects of the family influences the others, but not necessarily in a unidirectional manner. Meanings are developed and changed within the family and are also learned from the larger culture. There is a fluid relationship among these phenomena. Meanings evolve and alter over time not only through the influence of social and cultural values but through the particular experiences the family has and the effectiveness of the family as a social organization.

In our urbanized, industrialized society, there are certain prevailing values and functions relating to the family that are generally accepted by sociologists. For example, there is general agreement that the family is the social unit responsible for cultural transmission and continuity through socialization of the child. In this sense, a major part of the family's commitment involves preparing the child to carry on the business of society. One major impact of retardation is the ways the problem affects the family's ability to meet this commitment. One of the social implications of labeling a person retarded is to say that he is not qualified to carry on society's business and is therefore by definition deviant. By implication, the family, too, is deviant since it has failed in one of its major functions.

The degree to which the family accepts or rejects this definition of itself as deviant varies with its relationships with other

social institutions and the community. If the family lives in a culture which interprets retardation as God's will or a cross to be borne, the family may be able to reject and disregard the definition of itself as deviant, although it will probably not be able to reject it totally for the child who is labelled by special class placement or other attention as retarded.

Deviance has been defined as a determination placed on one social segment by another, usually more powerful social segment--the labelling segment. The fact that families of the lower social strata who have mildly retarded children seem to see themselves as deviant less than families of higher social strata does not disprove this premise. It is more suggestive that those who get less from the social system have less concern about conformity even though they accept and acknowledge pretty much the same roles as other groups. Yet it seems probable that parents of every social class would prefere that their children not be singled out and labelled as retarded.

In addition to being responsible for cultural transmission and continuity, the family is also responsible for the physical and psychological care of the child and for the social placement of the next generation of the family. This responsibility places unusual demands on the family when it has a retarded member. The second aspect of the responsibility, for social placement, becomes virtually impossible to fulfill. The family has to accept the fact that in its next generation, upward social mobility is one thing it cannot achieve.

Since the family is the principal social institution for meeting affectional as well as physical and psychological needs, the family with a retarded child is particularly vulnerable to dissolution and disorganization. Because of the great social and emotional stresses the retarded child places on the family, he can be a threat to family stability which makes it impossible for some family functions to be carried out.

One of the critical questions, then, is the degree of tolerance or acceptance that various subcultures will give deviant families who are unable to fulfill all their socially assigned functions. In a society where there is a highly specialized division of labor and therefore a high tolerance of differences among people, there will also be great precision in defining deviance at various levels. Therefore, more people will be labelled as deviant and the stigmatization of such labelling has a broad range of affects. Where does retardation fall in the range? This varies within subcultures and in terms of the particular goals of families.

When mental retardation is regarded as an aberration, there is great social emphasis on rehabilitation and cure. This means, in our society, that the relative lack of alterability of mental retardation is unacceptable to our value orientations. This is one reason so many families go from doctor to doctor year after year in fruitless pursuit of a "cure." The more emphasis there is in a family on individualism and change, and the greater the orientation toward the future, the more devastating the effects of retardation will be. Families and individuals who are present-oriented and fatalistic about the immodifiability of nature are less apt to interpret retardation as an intolerable affliction and more apt to regard it simply as a situation that has to be lived with. Families whose religion stresses a fatalistic acceptance of immodifiability are apt to accept and adapt to situations as they exist. This may be one reason Jewish and Catholic families are more apt to raise retarded children at home than to institutionalize them. Similarly, persons whose social positions are secure or who have no social position to worry about may be less threatened by a problem like retardation in the family than someone with upward mobility goals who is affiliated with a bureaucratic organization which stresses image and conformity.

One area of research that has been largely overlooked is the possibility that any kind of a crisis situation can reinforce and strengthen aspects of family life. There is a tendency to look only at the disorganizational effects and overlook the fact that a crisis condition like mental retardation may serve as a cohesive force.

Whatever meaning and impact retardation has for the family, its ability to cope with and adapt to the problem depends in part on the nature of its organization. Critical variables include family boundaries (that is, nuclear vs. extended family structures), health patterns within the family and community, allocation of roles, size and sex makeup of the family, and changes in family organization that occur over the family life cycle.

Farber's work, Dr. Tallman said, suggest that family organization reflects in part the strategies they use to achieve their goals. There are three principal types of family organization: child-oriented, home-oriented and parent-oriented. In the child-oriented family, there is a sharp division of labor, a concern for community status, and more emphasis on the children's gratification than on the gratification of the parents. In supporting the family as a social unit, the mother is allocated the responsibility for achieving gratification of the child's needs and the father maintains the community status. The home or domestically-oriented

family gives priority to socio-emotional norms and values of the family as a unit. In the parent-oriented family, there is a social-emotional emphasis and a focus on community status in terms of gratification of the parents. Marital integration is better in families using any of these orientations than in those using other "residual" strategies of family organization. This suggests that the specific allocation of roles is less important than agreement on the nature of whatever roles are assigned.

Another equally important area which needs additional study is what kinds of affectional coalitions exist within families. The addition of any new member to the family inevitably alters and threatens the existing affectional distribution. This is, of course, doubly true when the new member is retarded because of the potentialities for rejection or overprotection which exist. The realignments involve not only the parents but also other children. A close mother-son coalition may be disrupted by the shift of the mother's emotional commitment to the new member of the family, particularly if this member is retarded and in need of extra attention and care. This may throw the son out of the balance of family affectional bonds, or it may cause him to become closer to his father. There are many possible balances and realignments of family affectional relationships.

Family size may be an important organizational variable, particularly in terms of the division of labor when there is a retarded child requiring extra care. It would seem that the burden on any single member should be less when there are more family members to share it, especially if some of the older siblings are girls. But such a distribution of labor does not always occur, and large families often seem less able to cope with the problems of retardation than smaller ones. What are the factors that determine the efficiency of a family's coping mechanisms? What, for example, are the effects of a domestic orientation as opposed to a personal achievement orientation in the mother or the older children? What are the effects of the birth of a retarded child on family planning? How many children a family has is often affected by parental ambitions for their children, and what various members of the family can achieve is directly affected by the special stresses and strains of caring for a retarded child.

Ordinal position, another important variable, is keyed in with such variables as the age of the parents and their commitments to their other children. This pattern of relationship is complicated by the fact that the retarded child, whatever his actual ordinal position, gradually becomes the youngest child

in the family. Many parents look forward to the post-parental period when they will be free of responsibility for their children. For the parents of a retarded child, this day never comes. For some parents, this may be very difficult. For others, the continuing responsibility may be emotionally satisfying.

There are differences between the kinds of adaptability shown by the mothers and the fathers of retarded children. The mother's adaptability tends to be directly associated with the social competence of the child, while this appears to be a random relationship in the fathers. However, the role the father plays--for example, the amount of time he spends playing with the child--seems to bear a direct relationship to the adaptability of the mother. There is some evidence that children are less socially competent when there are no fathers in the home. This may perhaps reflect sex-related differences in social and emotional attitudes of the parents. In a sense, a retarded child represents a challenge to the social-emotional skills of the mother and her focus may be on preserving family harmony. This could mean placing less emphasis on developing the social competence of the child than on keeping things running smoothly.

The coping ability of the fathers of retarded children seems to be directly affected by the visibility of the child's retardation. Studies have shown that fathers of Mongoloids showed less adequate adaptive responses than fathers of other retarded children. This may reflect repugnance to the physical appearance of a severely retarded child. Mothers are less affected by appearance and respond more in terms of the relative intelligence and social competence of the child.

When we look at the family as a small group of interacting personalities, the principal issue becomes their ability to solve the day-to-day problems of caring for a retarded child. The family is relatively weak as a problem-solving structure, being composed essentially of two adults who are usually inexperienced in dealing with the general problems of parenthood or the special problems of retardation.

The power structure and the level of communication in the family may be critical factors in its effectiveness in problem solving. At times there may be a conflict between the power structure and the actual communication within the family. The father may be the dominant figure yet the most important and direct communication within the family may be a "collision" between mother and child. In other families, there may be a wheel structure with all information filtering into a central figure who is able to absorb it and channel it outward to where it should go.

Language as it affects cognitive style is a factor in the coping ability of families. It varies with social class. The amount of elaboration and specification that goes on in talking with the family and outside of it relates directly to the ability to focus on specific sorts of problems, and the greater articulateness of the upper socio-educational strata families may be a factor in their ability to cope more effectively with the problems of retardation in the home and to make use of the community and social resources available to help them. Participation of parents, and especially fathers, in voluntary organizations for parents of retarded children varies with the family's integration into the social system. The more adequate the family feels, the more willing the parents will be to identify themselves publicly in relation to retardation.

The social network within which a family operates affects the way it copes with the problems of retardation. A tightly knit network of relatives and friends may serve as a helping system which provides support of many kinds. On the other hand, if this network does not respond positively to the problem, the mother may feel more isolated than a mother in a loose-knit organizational pattern, and there may be more rejection of the child. In lower class families, where the men deal with the world and the women deal with the home and are fearful of the outside world, rejection by the social network can have a very destructive effect on the coping ability of the mother within the home and her ability to make use of outside resources.

There are many questions relating to retardation which lend themselves well to sociological research, Dr. Tallman said, but we may need to focus first on questions of general interest. We do not, for example, as yet know nearly enough about the ways communcation patterns and language styles affect the problem solving abilities of families either with or without special problems like retardation. Once we have this base knowledge, we will be able to ask a great many questions which relate specifically to the problems of the family with a retarded child.

General Discussion

Because of the informal structure of the conference, discussion ranged at random over a great many topics. Participants pointed out possible distorting factors in some of the statistics that had been presented; they talked of service gaps and the merits and demerits of various types of care. They spoke with the greatest feeling, however, of the problems that families face in adapting to retardation, for retardation, they recognized, has emotional as well as psychological, physiological and social components.

Many variables tend to skew statistics on the incidence and prevalence of mental retardation, a participant said. Mothers who have

retarded children are often at high risk in other ways also. They are apt, for example, to be women who are prone to repeated miscarriages for a variety of reasons. This distorts birth rate statistics, making it appear that families of retarded children have lower fertility rates than they actually have. The ordinal position of the child may also be different if the mother's earlier miscarriages are considered.

It is also somewhat misleading to use a statistical curve representing all social classes. It would be more pertinent to have a series of distribution curves specific to different social classes.

Within social classes, also, figures on the prevalence of different degrees of retardation may be misleading. Among children of the upper social classes who are identified as retarded, a high proportion have severe mental deficiency. This does not mean there are no mildly retarded children in these classes. They exist, but are often not so labelled because of the greater sensitivity of upper class parents to stigmatization and the greater resources they have for caring for their mildly retarded children without recourse to social agencies.

One of the gaps in services for the mentally retarded, several participants said, is the difficulty of reaching the parents of mildly retarded children. This is the group for whom the developmental potential is greatest, yet it is also the group for whom the least is done. Most services have traditionally been oriented toward severe retardation involving organic damage, and this same emphasis prevails in the voluntary parents' groups. Furthermore, even when low socioeconomic level mothers of retarded children are reached through well baby clinics or other services, they often are unable to put to use what they learn about child development and child rearing practices.

Perhaps one reason that our services to the retarded are not fully effective is that the emphasis is wrong, a participant suggested. For practical purposes, we might regard retardation primarily as the inability to cope with the environment of the moment. This suggests two possible approaches to therapy: 1) design a less demanding environment, or 2) increase the individual's skills in coping with his environment. Obviously, not all of the problems of all types of retardation can be solved by putting retardates in less demanding environments or by upgrading their skills, but we can do a great deal to teach parents how to be more effective therapists and teachers for their children.

As far as institutional care is concerned, it is true that the whole question needs to be clarified. There are many problems, and it is not always clear what causes them. For example, institutions for the retarded have high mortality rates up to age 10, but it is difficult to know whether this is because of the special conditions

of institutionalization or because the severely retarded child is apt to have nutritional and other problems which make him particularly vulnerable to infections and other illnesses.

It would, however, be a mistake to go overboard on the idea of small facilities. It is obviously bad when children in large institutions encounter 60 different mother surrogates in a week, all with approximately equal status, so that they are able to establish no bonds of individual affection. But the solution may lie in regrouping existing resources and personnel within the institutions to provide more stimulating and personalized relationships. This would make it possible to meet the needs of the children more effectively without involving unrealistically high costs.

The organization and structuring of institutional programs needs to be looked at also in terms of the peak admission periods. The biggest influx is during the adolescent years. The upswing is greater among girls, probably because of parental anxiety about what will happen to them as they mature sexually. Eighty-five percent of all people who are institutionalized as retarded are admitted before the age of 18. There is a second upswing in admissions when the retarded reach the age of 50 or 60 and are left without parents to take care of them. Parents usually anticipate this and arrange for institutionalization before they die. But institutions may not be the best solution for a retarded adult who has been in his own home all his life. One of the goals of the Association for Retarded Children is to arrange alternative types of placement in the community.

It should be remembered at all stages of the life of the retarded that care does not have to be an all-or-nothing proposition of total care in the home or total care elsewhere. Both the retarded individual and his family may profit from combinations of care that provide the special educational and other services that are needed, the opportunities for temporary relief from stress that families need, and the continuity of family affection the retarded member needs.

Institutional care per se is not necessarily bad, another participant agreed, but there are two important factors that affect development of the institutionalized mentally retarded child:

- the quality of program content
- the quality of people providing the care.

Multiple mothering is not necessarily bad, so long as opportunities for some close relationships exist. The assembly line technique is, of course, beyond acceptable boundaries.

Having a retarded child means a retarded life cycle for the whole family, not for the child alone, participants said. There is no escape for the mother or the father of a retarded child. It is not like going to the dentist for an hour or into the army for three years. These experiences, however painful or alien they may be, are bearable because they have a clearly defined end point. But the retardation of a child is a "life sentence" for the whole family.

This should not be true, other participants said. There tends to be a sentimentality of attitude that assumes that the focus of the whole family system should be on the ill or handicapped member. We tend to overlook the rights of the non-ill. In mental retardation, when families have a member who is a child for life, this places an awesome responsibility on the parents. For 30 years or more they are expected to focus their lives on what is essentially a deviant course. What should the boundaries of family responsibility be? This is an important philosophical and theoretical question.

Families have to take major responsibility for handling disability. Only about 5% of people with various types of handicaps are institutionalized. But the kinds of responsibility they assume should be based on realistic assessments of the needs of the entire family and of the changing social patterns which are affecting the necessity and the ability of families to provide long-term intensive care for their mentally retarded children. Fewer mothers now remain full time in the home. At the same time, society is becoming better able to provide special care, and families are better able to pay for it.

A deviant family member is apt to produce a deviant family preoccupied with his handicap. Is it in the best interests of the total family for the deviant member to remain in the home? Does it make sense for careers to be diverted and allocation of resources to be thrown out of proportion by the presence of the deviant member? What about the rights of other members of the family to live interesting, satisfying lives?

The attitudes of society complicate the management and adjustment problems of the families of retarded children, another participant said. They receive less social support than families of children with physical handicaps like polio. For example, more attention needs to be given to helping families prepare the retarded to be absorbed into the world of work. In Holland, where a high value is placed on work not only as a contribution to society but as something a person has a right to do, enormous efforts are put into helping families place the disabled in appropriate work situations.

Even with the best help society can provide, some families are going to be able to cope with the problems of mental retardation better than others. Every parent experiences a moment of anxiety at the child's birth. His first question is usually, "Is he all right?" But one of the most difficult periods for the parents of a mentally retarded child is when they first begin to discover their child is not developing normally but have not yet had professional confirmation. Experience is a factor in how well parents come through this period of stress and how well they can manage the retarded child. It is more difficult for inexperienced parents whose first child is retarded than for those who already have several children and are accustomed to the responsibilities of parenthood.

It may or may not be true that parents with several children adjust more easily to having a retarded child, another participant said. The more children there are in a family, the more difficult it becomes for them all to keep up to the goals the family had for the first child. This could have a depressing effect on the performance level of a later child who senses that he falls short of his parents' expectations in comparison with his older siblings.

The picture is not always entirely negative. Some families of retarded children manage astonishingly well under adverse circumstances. In some cases, having a retarded child seems to act as a stabilizing influence in the family. It gives purpose and meaning to what would otherwise be a bleak existence.

MENTAL RETARDATION RESEARCH

In keeping with the purpose of the conference, participants centered their discussion on the sociological aspects of mental retardation research. They discussed the unique contributions this discipline has to make to the field and the need for active efforts to stimulate more sociologists to undertake mental retardation research. They also discussed some of the methodological hazards of mental retardation research but outlined many specific researchable questions that need to be answered.

Sociological Aspects of Mental Retardation Research

Up to the present time, Chairman Michael Begab said, there has been an unexplained gap in mental retardation research. Many psychological, educational and biomedical studies have been done, but few sociological studies. This is particularly strange since priorities for sociological research center around family interaction and the interplay between sociological variables and family functioning--areas which have enormous significance in relation to mental retardation. They need to be explored as a basis for assessing the relative contributions of genetic factors, minor neurological deficits, and social forces in the etiology of mental retardation.

Although the National Institute of Child Health and Human Development is specifically interested in supporting sociological research in the mental retardation field, few grant applications of this type have been received. The Institute is committed to the concept of psycho-social deprivation as an area of research, and recognizes the need for longitudinal studies in this regard. Because psycho-social deprivation is such a broad phenomenon, three program areas of the Institute will be joining forces to help investigators define the most strategic directions for programs of prevention and treatment. One specific emphasis will be directed toward discovering which variables in the psycho-social deprivation syndrome cause some children to become retarded while others in similar living circumstances do not.

It is possible, Dr. Begab said, that one reason sociology has not become fully involved in mental retardation research is that there has been insufficient exchange of research information among various disciplines. Sociologists have not been made sufficiently aware of the contribution mental retardation studies can make to the understanding of family and social relationships. Conversely, the application of findings from sociological research on family and social theory have not been adequately disseminated and interpreted to the scientific community specifically interested in mental retardation.

If sociologists are to become interested in mental retardation research, a participant said, someone has to show them where the specific payoff lies. Why should the sociologist be more interested in doing research in retardation than in dozens of other disability categories? There is great competition among those interested in problems like cystic fibrosis, diabetes, heart disease and cancer to get behavioral scientists involved in their research. There is such a thing as ennui of affluence. With grants available in so many fields, the behavioral scientist is free to choose whatever interests him most. If he is to choose mental retardation, he must be shown what is unique about it as a study area which he cannot find in any other field.

What, exactly, is the role of the sociologist in relation to mental retardation, this participant asked. Is it to explore general processes like family reactions and acceptance, willingness to cooperate with institutions, etc? Perhaps the most interesting focus for sociologists is how mental retardation can be used to illuminate other relationships within the family. What do families really think and believe? What are their expectations of themselves and their children? What are their aspirations and goals? How are these reactions modified by the presence of mental retardation in the family?

Sociologists are interested in underlying theories of human behavior and social structure. If they are to be attracted into mental retardation research, they must be shown what it can contribute to their theoretical understanding. They need to be shown that mental retardation is one more resource they can use--another population to study, another mix of problems, another set of institutional arrangements which will shed light on their central research interests. Give sociologists strong enough grant support and show them what's in it for them, and they will do more mental retardation research, the participant concluded.

A number of other participants took exception to this point of view. It isn't a question of what mental retardation has to offer sociology, they said; the point is what does sociology have to offer mental retardation. Mental retardation is relatively non-visible as a social problem, as compared, for example, with juvenile delinquency, which has a very direct and visible impact on society. Sociologists will become interested in retardation as a field of research once they are led to see the links between mental retardation and broad sociological questions and what they can contribute to an understanding of both.

The principal research task of sociology is to locate and isolate structural and interaction factors in mental retardation,

a participant said. The research thrust needs to be toward prevention by focusing on socio-cultural determinants of mental retardation within the family and within society at large. The greatest appeal of mental retardation for the sociologist is the opportunity it provides to move away from routine and into a whole new area of intellectual challenge and stimulation; the opportunity, for example, to explore where mental retardation fits into a large general area of sociological concern like socialization.

Certain misconceptions about mental retardation need to be corrected, other participants pointed out. One is a question of labeling. Mental retardation as a label seems to peg it in the minds of many investigators as being in the province of clinical psychology. It does not suggest an immediate point of entry from sociological theory, so sociologists have difficulty in seeing its relevance to their interests in the structure, functioning and operation of groups. It might be helpful to drop the word "mental" from the designation and refer to "social retardation" when we wish to stress the sociological aspects of the problem.

The apparent lack of interest or even resistance of sociologists in mental retardation research may be essentially a matter of timing. There was a time when virtually no interest in retardation was shown by psychologists. Then one or two became interested, and the students of these investigators became interested. Eventually the "epidemic" spread until a great many psychologists became interested in mental retardation research. Sociologists just haven't "gotten the bug" yet. They are, however, interested in questions of the social competence of chronically disabled people, and it is only a short logical step from this to a specific interest in retardation, since a high percentage of the chronically disabled do have some degree of retardation.

It is also partly a question of making retardation research "fashionable", one participant indicated. Mental retardation is not the sort of thing people encounter in their general day-to-day activities, and it does not have the dramatic appeal of certain other types of handicaps. It is not, therefore, a problem that automatically occurs to investigators as an intrinsically interesting and productive area for research. Interest in particular research areas often follows a fad-like progression. Something stimulates an interest, money becomes available, a few top-rank people within a discipline start doing research and publishing their findings, and eventually the problem becomes a fashionable research focus.

One way to trigger off this kind of interest in mental retardation research would be to support an interdisciplinary conference

of leading behavioral scientists, commissioning each to write a paper based on his conceptual interest in the problem, and then publishing and broadly disseminating the papers. Symposia scheduled for the annual meetings of professional associations like the American Sociological Association, the Society for Research in Child Development, the American Anthropological Association, the American Psychological Association and others would stimulate additional interest. By offering appropriate fund support, it might also be possible to persuade groups like the Social Science Research Council to appoint committees of top-flight scientists who have been doing mental retardation research to define what contribution each discipline can make in giving this field of research the impetus it needs.

Behavioral scientists should be deeply involved in development of the mental retardation research centers from the very beginning of planning, not simply written into the budget as potential members of the research teams after the centers are established, several participants suggested. We need to evolve a pattern of cooperation in which people trained in the social and behavioral sciences and in the biological and medical sciences work together as co-equals on a common problem, maintaining at the same time strong roots back to their individual disciplines. In order to look effectively at the social and environmental factors in retardation, scientists of many disciplines--pediatricians, psychologists, sociologists, epidemiologists, anatomists, geneticists and others--need to rub shoulders daily. Each discipline will bring a different mode of thought and an awareness of particular variables so that research problems can be formulated sharply and accurately.

Agreeing that there is a distinct need for interdisciplinary research in mental retardation, Chairman Begab added that there is also a need for purely sociological research. When the idea of the mental retardation centers authorized under P.L. 88-164 was first conceptualized, it was intended that all the centers be multidisciplinary in focus. This proved to be impractical. It became apparent that universities interested in research of more limited focus might pull in other disciplines solely to fulfill the multidisciplinary requirement but would not really make full use of these groups. Consequently, it seemed wiser to build each center on the particular strengths of its university, even if the focus was a narrow one, rather than forcing all the centers into one mold. A good narrowly oriented center is better than a poor broadly oriented center. Both types are obviously needed.

The attitude of the universities will have a great deal to do with the level of interest social scientists maintain in mental retardation research, participants said. Too often, a sociologist

is added to a project as a sort of afterthought and has the feeling that his colleagues from the other university departments do not understand why he is there or what his role is. This may be further complicated if the research focus is applied rather than theoretical, because it is unfortunately true that advancement of sociologists up the academic ladder depends in many universities on their theoretical contributions "untainted" by connection with applied research. This sort of prejudice needs to be overcome and greater flexibility allowed investigators in the ways they choose to focus their research.

The support of training for mental retardation research needs to be closely tied in with the support of the actual research, several participants said. One weakness in social science research is the lack of investigators thoroughly grounded in research techniques.

NICHD is strongly interested in supporting both research and training and specifically hopes to encourage the interest of social scientists in mental retardation, Dr. Begab reiterated. Research and training are funded under separate mechanisms, but the relationship and the need for both is recognized. Universities and research groups interested in applying for grants should discuss their plans with the Institute at an early stage. Proposals are expensive and time consuming to develop, so it is well to be sure they are designed in ways that will give them a reasonable chance of acceptance under existing review and funding mechanisms.

Several participants suggested that the Institute encourage such early approaches by bringing prospective applicants in discussion before they actually develop their proposals. They might also be encouraged to apply outside the Government for "seed money" to cover the expenses of developing proposals. The National Association for Retarded Children, for example, has a limited amount of funds available for such purposes.

The Specific Research Potential

Mental retardation research is fraught with methodological problems, the participants said. One major problem is the lack of clear definitions of mental retardation discussed in an earlier section. In addition, many studies done thus far give erroneous impressions because they lump together all types of retardation; they generalize about the development of all mentally retarded children on the basis of studies of the development of institutionalized children; they compare the development of children reared at home with the development of children reared in institutions without specifying size, type, or quality; they ignore the fact that most children in large State institutions are from deprived socioeconomic

backgrounds, and that this is an important variable which affects their development; and they overlook the fact that children in institutions are apt to be those with more severe intellectual handicaps than those raised at home and cannot, therefore, be expected to develop as well.

Many studies generalize from very small samples, when the enormous number of interconnecting variables makes larger samples necessary if validity of data is to be assured. Most studies on the prevalence of mental retardation have depended on individuals being known to community health, welfare or education agencies. Studies based on a census-type operation might show quite a different overall incidence, and different age and social class distributions.

The diagnostic tests administered to children suspected of being retarded may not afford accurate measures. The test-making process itself may be so unfamiliar to the child that his performance fails to reflect his true capability. The performances of children of different socio-cultural backgrounds are often lumped together as if behavioral norms were the same in all social classes. In addition, the effect of environment on the test results is often overlooked, although one study has shown that children who have been living in institutions react differently to test-givers than those who have been living at home. The home-reared child reacts differently to different examiners, while the child reared in an institution tends to react the same way to all adults.

Many studies rely on parental memory--a notably unreliable source--for retrospective data about the child's early development. The biasing effects of parental and institutional values systems are often overlooked.

Despite these methodological handicaps, participants said, mental retardation offers many stimulating possibilities for sociological research. Sociological questions need to be asked, about the effects of mental retardation on the child and his family; the effects of various types of care; health, socioeconomic and value factors that affect the way a child develops; and the cultural, developmental, and behavioral norms of children of different ages and backgrounds.

SOME POSSIBLE RESEARCH QUESTIONS

Self Concept Formation

- What are the effects on a child of being publicly identified as retarded through assignment to special education classes or institutions?

- Does special education have long-term beneficial effects which outweigh the damage done by stigmatization?

- What are the consequences for a child's growth of continuous intellectual failure?

- What hierarchies of values are attached by parents to different forms of disability (physical handicaps, behavioral disturbances, intellectual deficits)? How are these transmitted to the child, and how do the resulting perceptions of himself affect his development?

- What are the effects on a child of his parents thinking him stupid? Can this, in itself, cause retardation?

Socialization Processes

- What special behavioral skills or personality traits (such as being compliant, non-combative, lovable) do children develop to compensate for retardation which enable them to get along in regular schools?

- What is the interrelationship between peer group and family influences?

- What are the unique characteristics of the father's role in mental retardation in relation to socialization of the child?

- Is the interaction between a father and a mentally retarded boy different from the interaction between a father and a normal boy in ways that affect development of sexual identity and ego identification?

- In what way does mental retardation limit the family's expectation of social growth?

Family Relationships and Child Rearing Patterns

- How does the impact of mental retardation on the child differ in situations where the mother is the principal socializing force and in situations involving multiple mother surrogates (large families, institutions)?

- What are the effects of different teaching styles of mothers? How do they achieve clarity of communication? How do they encourage or discourage curiosity? How do they build self-reliance?

- If some forms of functional retardation originate in the family environment, how can the group that has created the retardation--the family--serve as effective therapists to help the child cope with his problem? How can child-rearing practices in such families be modified to help the parents stop damaging their children and start functioning as developmental therapists? How can they be trained to maximize the child's developmental potential?

- What are the effects of having a mentally retarded child on the relationship between the parents?

- What are the effects on size of family and family planning? Do these vary with social class?

- What are the effects of mental retardation on normal siblings?

- How can the needs of the mentally retarded child and the rights of other members of the family to normal lives be balanced?

Social Systems, Networks and Institutions

- How much can legitimately be expected of parents as therapists and by what social supports must they be surrounded if they are to affect the child's development in positive ways?

- In what ways must the various social systems involved in care of the retarded rely on families to affect the behavior of the mentally retarded child?

- What are the interrelationships among all the institutional systems which intervene in mental retardation--the family, school, institutions, services of various kinds? Which ones are making effective contributions? What does each do to depress the child's level of performance? How do the various systems need to be altered to maximize each other's effectiveness in helping the child to develop to his maximum potential?

- What structures, functions and capabilities determine which families can provide adequate care for the mentally retarded child at home and which need to rely on other social institutions?

- When a family must devote its major efforts to care of a retarded child, what are the talent drains and other effects on the total society?

- In what types of families is mental retardation most prevalent (i.e., nuclear, extended, complete, incomplete)?

- What are the characteristics of different types of institutions for the mentally retarded in terms of organization, structure, types of personnel, use of personnel, size, financing, types of programs of education and therapy, value systems and other factors?

Patterns of Care, Treatment and Development

- Is a mentally retarded child better off being reared in his own home or elsewhere? Is the belief that a child thrives best in his own home valid or merely a sentimental assumption?

- What are acceptable alternative child-rearing settings for children outside their own homes?

- Is foster care a good alternative, or is its use based primarily on the concept that it is the closest substitute for the child's own home and must therefore be a good solution?

- Can good foster home placement help a child overcome retardation caused by environmental deprivation? If so, what are the implications of this finding for the development of programs and services?

- What are the effects on the child of different types of institutionalization?

- What systems of organization in care and services contribute most to the development of the child, and what ones undermine his development?

- What are the effects of use of child development-oriented personnel versus nursing-oriented personnel or custodial caretakers?

- What are the salient variables in child rearing, educational and institutional practice which affect the child's level of functioning?

- In what specific ways do the needs of retarded children differ from the needs of normal children or children with other types of handicaps?

Special Values, Attitudes and Expectations

- What are the value systems that underlie various types of care? Under what conditions do the institutions of society view different kinds of pathology favorably or unfavorably, and what is

the effect of these attitudes on the development of the mentally retarded child?

- What are the cues families get from the environment that begin to define for them that their child is retarded?

- What stereotypic misconceptions and value-laden reactions do families show when they first learn their child is retarded? What successive adaptations do they make, and how rapidly do they make them?

- What are the minimum levels of social competence a child needs to get along in the social system?

- What expectations do parents of different social classes, culture, educational levels, and levels of intelligence hold for the behavior, and development of their children? Are these realistically related to the developmental norms?

- What specific competencies are needed in given social classes in given communities; that is, what are the norms in specific settings?

- Is a child's range of functioning keyed in more closely with chronological age or socioeconomic and cultural background?

- What are the similarities and differences between mental retardation and other handicapping conditions as psychological phenomena?

Status and Roles

- How is a family's self-definition affected? How does the family of a retardate perceive itself, its children, its activities, its roles?

- How do families reconstitute their roles and reallocate their resources as a result of a diagnosis of mental retardation in a child? How do they prepare for the fact that they are going to have to support and care for this child throughout his life?

- What are the effects of having a retarded child on the social mobility of families? On career advancement, job change, geographic residence?

- What are the specific roles of various family members in direct and indirect care?

Parental Reactions and Coping Strategies

- How does the age at which retardation becomes apparent affect the reaction of the parents?

- What are the effects of long years of uncertainty about the child's condition, as opposed to the effects of handicapping diseases with sudden onset like polio?

- What are the common elements in patterns of parental adaptation to a diagnosis of mental retardation? What affects how soon they move through a period of shock reaction and mourning toward a focus on the needs of the child instead of on their own grief?

- Does mental retardation in a family create a deviant family in the sense of being unable to meet "normal objectives"? What degree of deviancy is created?

- How do different families assess their parental obligations to the mentally retarded child as opposed to their obligations to his siblings? How do these value systems influence family behavior in 1) crisis situations, and 2) chronic stress situations and decisions about the kind of care and treatment they provide for the mentally retarded child?

Social-environmental Factors in Etiology

- What are the day-to-day conditions in the lives of children that create subnormality?

- Do families create mental retardation (through deficient mother-child relationships, etc.) or do societal systems create it?

- What are the societal experiential factors which produce retardation? What dimensions are important; that is, what are the levels of impact of social class, subcultural groupings, area of residence and other factors?

- What are the specific differences that cause some children in the worst possible combination of environmental circumstances to become functionally retarded while others of the same intellectual level do not?

- What are the relationships between closely spaced pregnancies and mental retardation? Is the lack of time for physiological recovery of the mother a factor? Is the close spacing a function of low maternal intelligence level; or social class factors?

- What are the interrelationships between a mother's health and retardation in a child? To what degree is the mother's poor health a function of the stresses and burdens she has in caring for the handicapped child? In what ways does her poor health adversely affect his development?

FUTURE ACTION

As the conference drew to a close, the participants offered a number of suggestions for future action. These fell into two main categories: bibliographical materials and reviews of the present state of mental retardation research, and additional conferences to be sponsored by NICHD.

Throughout the conference there were repeated requests for annotated bibliographies of retardation studies which have implications for sociological research, and of sociological studies which have implications for mental retardation research. Several partial bibliographies, dealing with particular aspects of the problem, have been prepared. For example, a partial review of family mental retardation research prepared by Dr. Farber and his staff will soon be off the press.

A number of participants inquired whether there is any universal legal definition of mental retardation which is used as a basis for institutionalization. There is no such national definition, but some State laws do define it. A review of legislation relating to the family of the retardate and society has recently been completed by the Institute of Law, Psychiatry and Criminology at George Washington University.

What is most needed, the participants said, is something far more extensive than a bibliography or a review of the mental retardation literature, even a comprehensive one. Some group should be given a grant to abstract the common elements from the findings of all studies which have implications for mental retardation research and develop a set of generalizations and hypotheses from which sociological studies can be designed.

During the conference, one participant said, he had been hearing mostly bits and pieces; findings from studies done with 30 cases or 60 cases, non-random samples with no control studies. Perhaps NICHD could support a project to take a good look at all the research in the field, see which data are "hard" and which are "soft," and come up with a thorough critical analysis of what has been done and needs to be done. This should cover all the research out of several disciplines--sociology, psychology, social psychology, and others--done during the past 15-20 years. A great deal of excellent research has been done, especially since World War II, which is not being used; for example, research on the effects of various types of disabilities on families. There always seems to be a tendency to undervalue what has already been done and start from scratch as if each research thrust is totally new and unique. Several critical evaluations have been done, and any new analysis should make use of them as a starting point. With this kind of up-to-date analysis

at hand, mental retardation research could move beyond descriptive studies of populations to studies of causation, of cultural and social aspects of retardation, and of the best mechanisms for coping with the problem.

A number of participants expressed strong interest in additional NICHD-sponsored conferences and suggested central themes. Among these were:

- What can the social science disciplines do to clarify the definition of mental retardation?

- What constitutes social competence under a variety of circumstances?

  A conference on this topic would provide valuable conceptual bases for sociological research.

- What are the effects of stigmatization?

  Much valuable research on this subject has been done in relation to physical disability, leprosy, etc. which has implications for mental retardation.

- How effective are various types of social structures in relation to the mentally retarded, and what are appropriate alternatives to institutionalization?

The current conference, participants agreed, was a well directed effort of intellectual and scientific merit. It provided much useful food for further thought and action in the field of sociological studies of mental retardation.

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